

Complete Summary

GUIDELINE TITLE

Living with stroke. In: Clinical guidelines for stroke rehabilitation and recovery.

BIBLIOGRAPHIC SOURCE(S)

Living with stroke. In: National Stroke Foundation. Clinical guidelines for stroke rehabilitation and recovery. Melbourne (Australia): National Stroke Foundation; 2005 Sep 8. p. 41-6.

GUIDELINE STATUS

This is the current release of the guideline.

COMPLETE SUMMARY CONTENT

SCOPE
 METHODOLOGY - including Rating Scheme and Cost Analysis
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 CATEGORIES
 IDENTIFYING INFORMATION AND AVAILABILITY
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SCOPE

DISEASE/CONDITION(S)

- Stroke
- Consequences of stroke

Note: While stroke is discussed broadly in these guidelines, it is recognised that there are different types of stroke. It is noted that haemorrhagic stroke (particularly subarachnoid haemorrhage) is often excluded from some studies. Furthermore the prevalence of ischaemic stroke has meant that the evidence is predominantly derived from, and focussed on, this type of stroke.

GUIDELINE CATEGORY

Counseling
 Evaluation
 Management
 Rehabilitation

CLINICAL SPECIALTY

Family Practice
Geriatrics
Internal Medicine
Neurology
Nursing
Physical Medicine and Rehabilitation
Psychiatry
Psychology

INTENDED USERS

Allied Health Personnel
Health Care Providers
Health Plans
Nurses
Occupational Therapists
Patients
Pharmacists
Physical Therapists
Physician Assistants
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers

GUIDELINE OBJECTIVE(S)

- To provide a series of evidence-based recommendations related to stroke rehabilitation and recovery
- To help health care workers improve the quality and effectiveness of the care they provide to stroke patients

TARGET POPULATION

- Adults with stroke who are discharged from hospitalization to the community
- Carers of stroke survivors

INTERVENTIONS AND PRACTICES CONSIDERED

Management/Counselling

1. Self-management programs
2. Provision of therapies and services to improve or prevent deterioration in activities of daily living and exercise
3. Driving programs
4. Occupational therapy to increase leisure activity participation
5. Assessment and assistance for return to work
6. Sexuality issues information and assistance
7. Peer support: local stroke support groups
8. Counseling: educational, family, problem solving

9. Carer support: provision of information concerning local stroke support groups and other support services

MAJOR OUTCOMES CONSIDERED

- Rate of return to work
- Rate of return to driving
- Rate of participation in leisure activities
- Patient satisfaction with sexuality, exercise, and access to services
- Carer satisfaction with access to services and information
- Percentage of patients who self-manage their recovery
- Change in quality of life scores

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Systematic Searches and Literature Review

The systematic identification of relevant literature was conducted according to National Health and Medical Research Council (NHMRC) standards between May and October 2004.

Question Formulation

Clinical questions were developed by the Expert Working Group (EWG) to address interventions relevant to stroke rehabilitation and recovery. The questions generally queried the effects of a specific intervention and were developed in three parts: the intervention, the population and the outcomes. An example is "What is the effect of anticonvulsant therapy on reducing seizures in people with post-stroke seizures?" In this example, anticonvulsant therapy is the intervention, reduction of post-stroke seizures is the outcome, and the population is people with post-stroke seizures.

Finding Relevant Studies

To avoid duplication, the systematic literature search was undertaken in conjunction with the Stroke Therapy Evaluation Program (STEP) team from Scotland, who have been instrumental in identifying, appraising and collating the evidence for stroke care. The STEP team have developed and maintain 'effectivestrokecare.org', a fully indexed, searchable, web-enabled database of evidence for stroke management. STEP works in conjunction with the Cochrane Stroke Group.

Key words based on the components of the formulated question were used to guide searching. The search strategies were developed in partnership with the

STEP team to ensure comparability of the outcomes of the searches. Relevant systematic reviews were initially identified. Where no systematic review was found, primary studies were searched. STEP was initially used for each question although additional searches were required. In these cases standardised methodological filters were used for MEDLINE, CINAHL or psycINFO electronic databases. Updated searches were conducted prior to the end of the consultation period (early February, 2005), with significant literature included in order to provide the most up-to-date evidence.

Cost Analysis

Literature regarding the economic impact of stroke rehabilitation and recovery has been identified during the systematic development process of these guidelines. It is noted that the vast majority of the studies identified were conducted overseas and related to cost descriptions of individual factors or interventions, rather than economic evaluations comparing both the costs and effects of interventions.

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Levels of Evidence

I	Evidence obtained from a systematic review of all relevant randomised controlled trials.
II	Evidence obtained from at least one properly designed randomised controlled trial.
III-1	Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method).
III-2	Evidence obtained from comparative studies with concurrent controls and allocation randomised (cohort studies), case-control studies, or interrupted time-series with group.
III-3	Evidence obtained from comparative studies with historical control, two or more studies, or interrupted time series without a parallel control group.
IV	Evidence obtained from case series, either post-test or pre-test and post-test.

Clinical Practice Points

CPP	Recommended best practise based on clinical experience and expert opinion.
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METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Appraising and Selecting Studies

The Stroke Therapy Evaluation Program (STEP) team and the Expert Working Group (EWG) critically appraised the literature using a standardised checklist consistent with National Health and Medical Research Council (NHMRC) standards. The strength (study design and issues of quality), size of effect, relevance, applicability (benefits/harms) and generalisability were all considered. Examples of completed checklists can be found on the STEP website (www.effectivestrokecare.org). Where Level I or II evidence was unavailable the search was broadened to include lower levels of evidence.

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

The *Clinical Guidelines for Stroke Rehabilitation and Recovery* have been developed according to processes prescribed by the National Health and Medical Research Council (NHMRC) under the direction of an interdisciplinary Expert Working Group (EWG) (see Appendix 1 in the original guideline document). Consultation from other individuals and organisations was also included in the development process in line with NHMRC standards. The EWG has worked through a collaborative process, and networked with a number of formal and informal groups and individuals from around Australia and overseas.

Consumer Involvement

Consumer input has been a key component in the development process. Three consumers were included in the EWG and have been involved in every phase of the development process, including the development of the clinical questions to guide the literature searching. In addition a number of consumer organisations participated in the consultation process including the State Stroke Associations, the Health Consumer Council of WA and the Carers Australia.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

The level of the evidence highlights the methodology of the studies contributing to the evidence that underpins the recommendations. However this does not always translate into an equivalent strength of the recommendation for two reasons: studies vary in quality and different studies may produce conflicting results. The Expert Working Group (EWG) has therefore used 'may' or 'should' to indicate the strength of the recommendation. 'May' is used when the evidence is not clear cut

or when there is a wide range of opinions relating to a specific intervention; 'should' is used when there is clear outcomes of all relevant research or a narrow range of opinion. Key references for each guideline are also included. Where no level I, II, III or IV evidence was available but there was sufficient consensus of the EWG, clinical practice points have been provided.

COST ANALYSIS

Community Rehabilitation

Economic evaluations of community rehabilitation are limited to cost-description studies. One systematic review identified four trials comparing different models of community care and found conflicting results. Three studies were undertaken in the UK and one in Sweden. Two studies comparing homebased rehabilitation to a day hospital or outpatient rehabilitation models reported consistent increases in costs for home-based care between 26-27%; however, this increase was not found to be significant. Another study found physiotherapy services were 38% lower (statistically significant) for home-based care compared to a day hospital. The fourth study found community rehabilitation (home-based) was of similar costs in the first twelve months when compared to hospital rehabilitation. Two included studies noted that the cost burden was shifted from hospital services to home help or social services. The authors of the review, however, stated that no conclusions could be drawn.

From this literature it is not possible to make conclusions regarding the cost effectiveness of any one model of community rehabilitation and whether or not any additional costs that may be incurred result in more health gains than current practice.

Section 5 *Resource Implications* in the original guideline document outlines the economic evidence for aspects of stroke recovery and rehabilitation. The section aims to be useful in guiding decisions about the structure of services and may be used by those who plan or organise care.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Public consultation was undertaken, with the draft document circulated to relevant professional bodies, interested individuals, consumers and consumer organisations. A public notice was also published in *The Australian* newspaper. Feedback received during consultation was considered by the Expert Working Group (EWG) and the draft document amended. A formal letter of reply was sent to all individuals and organisations that provided feedback during this period outlining the response taken by the EWG.

The outcomes of the consultation period suggested:

- Greater focus on person-centred care
- Greater focus on rural and remote issues
- Minor clarification on relevant literature
- Revision of the roles of stroke team members

Many points made during consultation related to grammatical or semantic interpretations and the EWG was able to make changes to correct or clarify certain points. In one instance, an additional study was identified. Overall the consultation process provided valuable assistance by increasing the accuracy and comprehensiveness of the document.

These guidelines were approved by the National Health and Medical Research Council at its 158th Session on 8 September 2005, under section 14A of the National Health and Medical Research Council Act 1992.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

The levels of evidence supporting the recommendations (I-IV) and clinical practice points (CPP) are defined at the end of the "Major Recommendations" field.

Activity and Participation in the Community

Self-management

People with stroke who do not have cognitive impairment should be made aware of the availability of generic self-management programs before discharge from hospital and be supported to access such programs once they have returned to the community. (**Level II**, [Lorig et al., 2001; Lorig et al., 1999; Fu et al., 2003])

Stroke-specific programs for self-management may be provided to people who require more specialised programs. (**CPP**)

A collaboratively developed self-management care plan may be used to harness and optimise self-management skills. (**CPP**)

Activities of Daily Living (ADL) and Exercise

People living in the community who have difficulties with ADL should have access, as appropriate, to therapy services to improve, or prevent deterioration in, ADL. (**Level I**, [Outpatient Service Trialists, 2002])

People who are living in the community more than 6 months after their stroke should have access to interventions to improve fitness and mobility. (**Level II**, [Ouellette et al., 2004; Chu et al., 2004; Ada et al., 2003])

People living in the community should be provided with information (e.g., alternative transport options, resuming driving, ADL and exercise opportunities/services) to facilitate increased outdoor journeys and therefore

greater participation within the community. The information provided should also be supplemented by other simple strategies (e.g., encouragement, use of appropriate aids/appliances, approaches to overcoming fear) by an appropriate health professional. (**Level II**, [Logan et al., 2004])

General practitioners should refer to allied health professionals where necessary when undertaking routine medical review of people with stroke. (**CPP**)

Driving

People with stroke who wish to return to driving may be offered a visual attention retraining program or traditional perceptual training. (**Level II**, [Mazer et al., 2003])

The National Guidelines for Driving (Austroads) and relevant state guidelines should be followed for all issues relating to driving following a stroke. (**CPP**)

People with stroke who wish to return to driving should be offered an opportunity to undertake an occupational therapy driving assessment, unless there are medical contraindications. (**CPP**)

Leisure

Targeted occupational therapy may be used to increase participation in leisure activities. (**Level I**, [Walker et al., 2004])

Return to Work

People with stroke who wish to work should be offered assessment and assistance to resume or take up work. (**CPP**)

Sexuality

People with stroke and their carers should be offered:

- The opportunity to discuss issues relating to sexuality with an appropriate health professional; (**CPP**)
- Written information addressing issues relating to sexuality post-stroke. (**CPP**)

Any interventions should address psychosocial aspects as well as physical function. (**CPP**)

Support

Peer Support

Stroke survivors should be provided with information about the availability and potential benefits of a local stroke support group and/or other sources of peer support prior to discharge from the hospital. (**CPP**)

Counselling

Counselling services should be made available to all stroke survivors and their families and may take the form of:

- An active educational counselling approach; (**Level I**, [Bhagal et al., 2003])
- Information supplemented by family counselling; (**Level II**, [Clark, Rubenach, & Winsor, 2003])
- A problem-solving counselling approach. (**Level II**, [Evans et al., 1988])

Carer Support

Carers of stroke survivors should be provided with:

- Information about the availability and potential benefits of local stroke support groups, at or before the person's return to the community; (**Level II**, [van den Heuvel et al., 2002]; **Level III-2**, [van den Heuvel et al., 2000])
- Support by health professionals starting early after the person's stroke. (**CPP**)

Carers of stroke survivors should be offered services to support them after the person's return to the community. Such services should use a problem-solving or educational-counselling approach. (**Level II**, [van den Heuvel et al., 2002; Hartke & King, 2003; Grant, 1999]; **Level III-2**, [van den Heuvel et al., 2000])

Definitions:

Levels of Evidence

I	Evidence obtained from a systematic review of all relevant randomised controlled trials.
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III-1	Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method).
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IV	Evidence obtained from case series, either post-test or pre-test and post-test.

Clinical Practice Points

CPP	Recommended best practise based on clinical experience and expert opinion.
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CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

REFERENCES SUPPORTING THE RECOMMENDATIONS

[References open in a new window](#)

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is identified and graded for each recommendation (see "Major Recommendations").

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

- Appropriate planning and coordination of services for stroke patients who have been discharged to the community
- Return of stroke survivors, as far as possible, to their pre-stroke levels of activity and engagement with the community
- Optimal quality of life for stroke survivors

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

- This document is a general guide to appropriate practice, to be followed subject to the clinician's judgement and the patient's preference in each individual case. The guidelines are designed to provide information to assist decision-making and are based on the best evidence available at the time of publication.
- The guidelines should not be seen as an inflexible recipe for stroke care; rather, they provide a framework that is based on the best available evidence that can be adapted to local needs, resources and individual circumstances.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

Reviewing the evidence and developing evidence-based recommendations for care involves only the first steps to ensuring that evidence-based care is available. Following publication of the *Clinical Guidelines for Stroke Rehabilitation and Recovery*, the guidelines must be disseminated to all those who provide care of

relevance to stroke rehabilitation and recovery, who may then identify ways in which the guidelines may be taken up at a local level.

Strategies by which guidelines may be disseminated and implemented include:

- Distribution of education materials - for example: mailing of guidelines to members of the target audience.
- Educational meetings - for example: interdisciplinary conferences.
- Educational outreach visits - for example: one on one visits by trained educators for short periods of time or visits by trained educators for longer periods of time; local opinion leaders (with brief training, they may provide covering letters for guidelines mailed to colleagues or host meetings; with training for longer periods of time, they may head task forces, etc).
- Audit and feedback - for example: regular, frequent e-mails to clinicians with computer generated reports on compliance with guidelines.
- Reminders - for example: computer generated alerts and flags.

A systematic review of dissemination and implementation strategies found that there was insufficient evidence of the effectiveness of these interventions. Methodological weaknesses, poor reporting of the study setting and uncertainty about the generalisability of the results were the prime reasons that made interpretation difficult. The review also indicated that single interventions may or may not be as effective as multifaceted interventions and there is no relationship between the number of interventions and the effect of the interventions.

All of the above strategies may therefore be considered and used where appropriate for implementation of the *Clinical Guidelines for Stroke Rehabilitation and Recovery*. Health professionals are encouraged to identify the barriers and facilitators to evidence-based care within their environment when determining the best strategy for local needs. Implementation of the Guidelines may be supported by existing resources and networks. These include:

- The *Stroke Services in Australia* report, which outlines how stroke services may be organised in different parts of Australia and the resources that may be needed to do this (available at www.strokefoundation.com.au).
- The *Stroke Care Pathway*, which provides a checklist addressing key processes of care as outlined in both documents (Acute, and Rehabilitation and Recovery) and a guide to developing local protocols.
- The *Australasian Stroke Unit Network*: comprising health professionals from acute and post-acute settings across Australasia from different disciplines who are interested in stroke care (see www.asun.com.au).

The following principles, relating to the *Clinical Guidelines for Stroke Rehabilitation and Recovery*, are essential to the planning and delivery of rehabilitation and recovery services and should be considered when implementing the evidence in a local setting:

- Focus on and respect for the individual needs of each person with stroke, with care tailored specifically to those needs.
- Inclusion of the person with stroke and, where relevant, the family in the interdisciplinary team and, in particular, in setting realistic and achievable

- rehabilitation goals in order to facilitate informed decision-making, empowerment, autonomy and person-centred care.
- Recognition that the person with stroke is part of a family and a community, with all the demands, needs and strengths that this entails.
 - Respect for cultural and other differences and the different service delivery needs that these may entail. Care, and particularly information, should be provided using an appropriate language and format.
 - Equity of access, across geographic, cultural, linguistic and socioeconomic groups, to the full range of rehabilitation services.
 - Continuity of care across acute, rehabilitation and community services, to enable each person with stroke to move smoothly from one to another.

See the original guideline document for further discussion of the implications for service equity.

For information about availability, see the "Availability of Companion Documents" and "Patient Resources" fields below.

IMPLEMENTATION TOOLS

Patient Resources
Quick Reference Guides/Physician Guides

For information about [availability](#), see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Getting Better
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Living with stroke. In: National Stroke Foundation. Clinical guidelines for stroke rehabilitation and recovery. Melbourne (Australia): National Stroke Foundation; 2005 Sep 8. p. 41-6.

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2005 Sep 8

GUIDELINE DEVELOPER(S)

National Stroke Foundation (Australia) - Private Nonprofit Organization

SOURCE(S) OF FUNDING

Australian Government Department of Health and Ageing

GUIDELINE COMMITTEE

Expert Working Group

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Group Members: Dr Michael Pollack (*Co-chair*) Director, Hunter Stroke Service; Rehabilitation Physician, John Hunter Hospital; Dr Erin Lalor (*Co-chair*) Chief Executive Officer, National Stroke Foundation; Dr Louise Ada, Physiotherapist, University of Sydney; Prof Justin Beilby, Professor of General Practice, University of Adelaide; Dr Janice Collier, Physiotherapist, National Stroke Research Institute; Ms Cindy Dilworth, Speech Pathologist, Royal Brisbane and Women's Hospital; Ms Louise Gustafsson, Occupational Therapist, University of Queensland; Mr Kelvin Hill, Project Manager, National Stroke Foundation; Ms Louise Jordan, Manager of Clinical Service Delivery, Hunter Stroke Service; Dr Sharon Kilbreath, Physiotherapist, University of Sydney; Prof Richard Lindley, Professor of Geriatric Medicine, University of Sydney; Geriatrician, Westmead Hospital; Mr Ian Murdoch, Consumer Representative, Queensland Stroke Association; Mr John Norton, Consumer Representative, Bendigo; Ms Debra O'Conner, Director of Health Promotion, Dianella Community Health; Ms Jane Phelan, Consumer Representative, Melbourne; Ms Jenny Pilgram, Nurse Educator, Royal District Nursing Service, Melbourne; Dr Rene Pols, Deputy Director of Human Behaviour and Health Research Unit, Flinders University; Dr Jonathan Sturm, Neurologist, Gosford Hospital

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

ENDORSER(S)

Australasian Faculty of Rehabilitation Medicine - Professional Association
Australasian Stroke Unit Network - Professional Association
Australian College of Rural and Remote Medicine - Professional Association
Australian Physiotherapy Association - Medical Specialty Society
Australian Society for Geriatric Medicine - Medical Specialty Society
Dietitians Association of Australia - Professional Association
Occupational Therapy Australia - Professional Association
Royal Australian and New Zealand College of Psychiatrists - Professional

Association
Royal Australian and New Zealand College of Radiologists - Professional Association
Royal College of Nursing - Professional Association
Speech Pathology Australia - Medical Specialty Society
Stroke Society of Australasia - Disease Specific Society

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) from the [National Stroke Foundation \(Australia\) Web site](#).

Print copies: Available from the National Stroke Foundation (Australia), Level 7, 461 Bourke Street, Melbourne Victoria 3000, Australia.

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- Physiotherapy. Concise guidelines. Stroke rehabilitation and recovery. Melbourne (Australia): National Stroke Foundation; 2008 Mar. 4 p.
- Speech pathology. Concise guidelines. Stroke rehabilitation and recovery. Melbourne (Australia): National Stroke Foundation; 2005 2 p.
- Occupational therapy. Concise guidelines. Stroke rehabilitation and recovery. Melbourne (Australia): National Stroke Foundation; 2008 Mar. 4 p.
- Dietetics. Concise guidelines. Stroke rehabilitation and recovery. Melbourne (Australia): National Stroke Foundation; 2008 Mar. 2 p.

Electronic copies: Available in Portable Document Format (PDF) from the [National Stroke Foundation \(Australia\) Web site](#).

Print copies: Available from the National Stroke Foundation (Australia), Level 7, 461 Bourke Street, Melbourne Victoria 3000, Australia.

PATIENT RESOURCES

The following are available:

- Driving after stroke. Fact sheet 1. Melbourne (Australia): National Stroke Foundation; 2008 July. 4 p.
- Sexuality after stroke. Fact sheet 2. Melbourne (Australia): National Stroke Foundation; 2008 July. 2 p.
- Depression after stroke. Fact sheet 3. Melbourne (Australia): National Stroke Foundation; 2008 July. 2 p. See the related QualityTool summary on the [Health Care Innovations Exchange Web site](#).
- Fatigue after stroke. Fact sheet 4. Melbourne (Australia): National Stroke Foundation; 2008 July. 2 p.

- Medication after stroke. Fact sheet 5. Melbourne (Australia): National Stroke Foundation; 2008 July. 4 p.
- Thinking and perception after stroke. Fact sheet 6. Melbourne (Australia): National Stroke Foundation; 2008 July. 4 p.
- Diet after stroke. Fact sheet 7. Melbourne (Australia): National Stroke Foundation; 2008 July. 2 p.
- Movement and exercise after stroke. Fact sheet 8. Melbourne (Australia): National Stroke Foundation; 2008 July. 2 p.
- Communication after stroke. Fact sheet 9. Melbourne (Australia): National Stroke Foundation; 2008 Sept. 4 p.

Electronic copies: Available in Portable Document Format (PDF) from the [National Stroke Foundation \(Australia\) Web site](#).

Print copies: Available from the National Stroke Foundation (Australia), Level 7, 461 Bourke Street, Melbourne Victoria 3000, Australia.

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NGC STATUS

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Date Modified: 7/27/2009

